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DECISIONS RELATED TO THE BEGINNING AND END OF LIFE

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Summary

The traditions and practices of medicine provide an important reference point for medical ethics because they are based on the obligation to protect and promote the health-related interests of the patient. Medical ethics should be understood to be the disciplined study of morality in medicine and to concern the obligations of physicians and healthcare organizations to patients as well as the obligations of patients. Ethics is an essential dimension of maternal critical care. Maternal critical care is ethically more complex when the fetus as a patient. The physiacn's role is to explain to the pregnant patient before critical care is initiated its nature as a trial of management, The physician should explain both the short-term and long-term goals and the possibility that they might not be achieved. It is better for patients and their families to prevent ethical conflicts. Preventive ethics helps to build and sustain a strong physician-patient relationship.

Key words

Medical ethics, patient, non-maleficence, fetus as a patient, directive counseling.

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РЕШЕНИЯ, СВЯЗАННЫЕ С НАЧАЛОМ И ОКОНЧАНИЕМ ЖИЗНИ

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Резюме

Традиции и практики медицины являются важными эталонами медицинской этики, поскольку в их основе лежит обязательство защищать и способствовать интересам пациента, связанным со здоровьем. Медицинскую этику следует понимать как упорядоченное исследование нравственности в медицине с учетом обязательств врачей и организаций здравоохранения перед пациентами, а также обязательств пациентов. Этика является существенным параметром интенсивной терапии матерей. Интенсивная терапия матерей представляется более сложной с этической точки зрения, если пациентом является нерожденный плод. Роль врача заключается в том, чтобы перед началом интенсивной терапии разъяснить беременной пациентке, что данная терапия является попыткой решения проблемы. Врач должен разъяснить, какие краткосрочные и долгосрочные цели и возможности могут не быть достигнуты. Для пациентов и их семей лучше предотвращать этические конфликты. Профилактическая этика помогает создать и поддерживать прочные отношения между врачом и пациентом.

Ключевые слова:

Медицинская этика, пациент, отсутствие злого умысла, плод как пациент, рациональное консультирование.

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Introduction

Ethics is an essential dimension of maternal critical care [10]. This is an area of clinical practice with a high potential for ethical conflict in all cultural and national settings around the world. Rather than wait for such conflict to occur, it is far better for patients, their families, and healthcare professionals to anticipate and seek to prevent ethical conflicts. This chapter, therefore, emphasizes a transcultural, transnational, and transreligious preventive ethics approach that appreciates the potential for ethical conflicts and adopts ethically justified strategies to prevent those conflicts from occurring. Preventive ethics helps to build and sustain a strong physician-patient relationship. The chapter commences with a definition of ethics, medical ethics, and the fundamental ethical principles of medical ethics: beneficence and respect for autonomy. The ethical concept of the fetus as a patient is then considered before continuing to define critical care as a trial of management, with short- and long-term goals. Finally, an ethical framework for a preventive ethics approach to maternal critical care is provided.

Ethics, medical ethics, and ethical principles

Ethics has been understood in the global histories of philosophy and theology to be the disciplined study of morality. Medical ethics should, therefore, be understood to be the disciplined study of morality in medicine and to concern the obligations of physicians and healthcare organizations to patients as well as the obligations of patients. Medical ethics should not be confused with the many sources of morality that exist in particular societies. These can include, but are not limited to, law, the world's religions, ethnic and cultural traditions, families, the traditions and! practices of medicine (including medical education and training), and personal experience. Medical ethics since the eighteenth century European and American Enlightenments has been secular [6]. It makes no reference to God or revealed tradition, but to what rational discourse requires and produces. At the same time, secular medical ethics is not intrinsically hostile to religious beliefs. Therefore, ethical principles and virtues should be understood to apply to all physicians in all countries, regardless of their personal religious and spiritual beliefs [1]. The resulting professional responsibility model of obstetric ethics [3] is transnational and transcultural.

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The traditions and practices of medicine provide an important reference point for medical ethics because they are based on the obligation to protect and promote the health-related interests of the patient. This obligation tells physicians what morality in medicine ought to be, but in very general abstract terms. Providing a more concrete, clinically applicable account of that obligation is the central task of medical ethics, using ethical principles [1,6,10].

The ethical principle of beneficence in its general meaning and application requires one to act in a way that is expected reliably to produce the greater balance of benefits over harms in the lives of others. To put this principle into clinical practice requires a reliable account of the clinical benefits and harms relevant to the care of the patient, and of how those clinical goods and harms should be reasonably balanced against each other when not all of them can be achieved in a particular clinical situation, such as a request for an elective cesarean delivery. In medicine, the principle of beneficence requires the physician to act in a way that is reliably expected to produce the greater balance of clinical benefits over harms for the patient [1,6,10].

Beneficence-based clinical judgment has an ancient pedigree, with its first expression found in the Hippocratic oath and accompanying texts [8]. Beneficence-based clinical judgment makes an important claim: to interpret reliably the health-related interests of the patient from medicine's perspective. This perspective is provided by accumulated scientific research, clinical experience, and reasoned responses to uncertainty. As rigorously

evidence-based, beneficence- based judgment is, therefore, not the function of the individual clinical perspective of any particular physician, it should not be based merely on the clinical impression or intuition of an individual physician. On the basis of this rigorous clinical perspective, focused on the best available evidence, beneficence-based clinical judgment identifies the benefits that can be achieved for the patient in clinical practice based on the competencies of medicine. The benefits that medicine is competent to seek for patients are the prevention and management of disease, injury, disability, and unnecessary pain and suffering, and the prevention of premature or unnecessary death. Pain and suffering become unnecessary when they do not result in achieving the other goods of medical care, for example allowing a woman to labor without effective analgesia [1,6,10].

Non-maleficence is an ethical principle that obligates the physician to prevent causing harm. Non- maleficence should be best understood as expressing the limits of beneficence. Non-maleficence is better known to physicians as primum non nocere, or "first do no harm". This commonly invoked dogma is really a Latinized misinterpretation of the Hippocratic texts, which emphasized beneficence while avoiding harm when approaching the limits of medicine. Non-maleficence should be incorporated into beneficence- based clinical judgment: when the physician approaches the limits of beneficence-based clinical judgment (i.e. when the evidence for expected benefit diminishes and the risks of clinical harm increase), then the physician should proceed with great caution. The physician should be particularly concerned to prevent serious, far-reaching, and irreversible clinical harm to the patient [1,6,10].

There is an inherent risk of paternalism in beneficence-based clinical judgment that must be responsibly managed. Beneficence-based clinical judgment, when it is mistakenly considered to be the sole source of moral responsibility and therefore moral authority in medical care, invites the unwary physician to conclude that beneficence-based judgments can be imposed on the patient in violation of his/her autonomy. Paternalism is a dehumanizing response to the patient and, therefore, should be avoided in the practice of maternal critical care.

The ethical principle of respect for autonomy stands in contrast with the principle of beneficence. Respect for autonomy obligates the physician to empower the patient to make informed decisions about his/her medical care and to implement his/her value-based preferences, unless there is compelling ethical justification for not doing so. The pregnant patient increasingly brings to her medical care her own perspective on what is in her interest. The principle of respect for autonomy translates this fact into autonomy-based clinical judgment. Because each patient's perspective on his/her interests is a function of his/her values and beliefs, it is impossible to specify the benefits and harms of autonomy-based clinical judgment in advance. Indeed, it would be inappropriate for the physician to do so, because the definition of benefits and harms and their balancing are the prerogative of the patient. Not surprisingly, autonomy-based clinical judgment is strongly anti- paternalistic in nature [1,6,10].

Beneficence and respect for autonomy both shape the informed consent process. The physician has the beneficence-based obligation to identify and present to the patient all of the medically reasonable forms of clinical management for the management of the condition, disease, or injury. "Medically reasonable" means that a form of clinical management is physically available, technically possible, and supported in evidence-based reasoning as having an outcome that, on balance, will be clinically beneficial. There is no ethical obligation to offer clinical management that meets only the first two criteria. Failure to recognize this creates preventable ethical conflict in critical care. The physician should describe the nature and expected outcomes of medically reasonable alternatives, along with their expected risks and how these will be managed should they occur.

The pregnant patient's role has iterative steps. She should (a) pay attention; (b) absorb, retain, and recall information about her condition and the medically reasonable alternatives for managing it; (c) understand these matters; (d) understand that these matters apply to her; (e) evaluate the outcomes of the medically reasonable alternatives based on her own values (i.e. what is important to her); and (f) express a value-based preference. The physician has a role to play in supporting each of these steps. The physician should recognize the capacity of each patient to deal with medical information (and not to underestimate that capacity), provide information (i.e. disclose and explain all medically reasonable alternatives), and recognize the validity of the values and beliefs of the patient. The physician should try not to interfere with but, when necessary, to assist the patient in her evaluation and ranking of diagnostic and therapeutic alternatives for managing her condition and then elicit and implement the patient's value-based preference [10].

In the USA, the legal obligations of the physician regarding informed consent were established in a series of cases during the twentieth century. In 1914, Schloendorff v. The Society of The New York Hospital established the concept of simple consent, that is, whether the patient says yes or no to medical intervention [7,12]. To this day in the medical and bioethics literature, this decision is quoted: "Every human being of adult years and sound mind has the right to determine what shall be done with his body, and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages" [12]. The legal requirement of consent further evolved to include disclosure of information sufficient to enable patients to make informed decisions about whether to say yes or no to medical intervention [7].

The ethical concept of the fetus as a patient

The ethical concept of the fetus as a patient is essential to maternal critical care in all cultural and national settings.

Developments in fetal diagnosis and management strategies to optimize fetal outcome have become widely accepted, encouraging the development of this concept. This concept has considerable clinical significance because, when the fetus is a patient, directive counseling (i.e. recommending a form of management) for fetal benefit is appropriate, and when the fetus is not a patient, non-directive counseling (i.e. offering but not recommending a form of management for fetal benefit) is appropriate. However, there can be uncertainty about when the fetus is a patient. One approach to resolving this uncertainty would be to argue that the fetus is or is not a patient in virtue of personhood, or some other form of independent moral status. The following discussion shows that this approach fails to resolve the uncertainty therefore, supports an alternative approach that resolve the uncertainty.

One prominent approach for establishing whether or not the fetus is a patient has involved attempts show whether or not the fetus has independent moral status. Independent moral status for the fetus means that one or more characteristic that the fetus possesses: in and of itself and, therefore, independently of the pregnant woman or any other factor, generates and grounds obligations to the fetus on the part of pregnant woman and her physician. Despite an ever expanding theological and philosophical literature on this subject, there has been no closure on a single authoritative account of the independent moral status of the fetus. This is an unsurprising outcome because given the absence of a single method that would authoritative for all of the markedly diverse theological and philosophical schools of thought involved in endless debate, closure is impossible. For closure ever' to be possible, debates about such a final authority within and between theological and philosophical traditions would have to be resolved in a way satisfactory to all, an inconceivable intellectual and cultural event In terms of the independent moral status of the fetus, the concept of the fetus as a patient has no stable or clinically applicable meaning. Maternal-fetal medicine, therefore, should abandon these futile attempts to understand the ethical concept of the fetus as a patient in terms of independent moral status of the fetus and turn to an alternative approach that makes it possible to identify ethically distinct senses of the fetus as a patient and their clinical implications for directive and non-directive counseling [10].

This alternative approach is based on the concept of the dependent moral status of the fetus and the recognition that being a patient does not require that one possesses independent moral status. Rather, being a patient means that one can benefit from the applications of the clinical skills of the physician. Put more precisely, a human being becomes a patient when two conditions are met: that a human being is presented to the physician, and that clinical interventions exist that are medically reasonable in that they are reliably expected to result in a greater balance of clinical benefits over harms for the human being in question. These two criteria are obviously transcultural, transnational, and transreligious. This is the sense in which the ethical concept of the fetus as a patient should be understood in all cultural and national settings.

The authors have argued elsewhere that beneficence-based obligations to the fetus exist when e fetus is reliably expected later to achieve independent moral status as a child and person [10]. That is, the is a patient when the fetus is presented for medical interventions, whether diagnostic or therapeutic, that reasonably can be expected to result in a greater ice of goods over harms for the child and person the fetus can later become during early childhood. The ethical significance of the concept of the fetus as a patient, therefore, depends on links that can be established between the fetus and its later achieving independent moral status.

The viable fetal patient

One such link between the fetus and its later achieving independent moral status is viability. Viability, however, must be understood in terms of both biological and technological factors. It is only by virtue of both factors that a viable fetus can exist ex utero and thus achieve independent moral status. When a fetus is viable – that is, when it is of sufficient maturity so t it can survive into the neonatal period and achieve independent moral status given the availability of the requisite technological support – and when it is presented to the physician, the fetus is a patient.

Viability exists as a function of biomedical and technological capacities, which vary in different parts of the world. As a consequence, there is, at the present J time, no worldwide, uniform gestational age to define viability. In developed countries, we believe, viability presently occurs at approximately 24 weeks of gestational age [4]. Clearly, in less developed countries viability can occur later because of variation in the technological ability to support premature infants. This variability may affect decision making about intrapartum management and resuscitation of the neonate.

The previable fetal patient

The only possible link between the previable fetus and the child it can become is the pregnant woman's autonomy. This is because technological factors cannot result in the previable fetus becoming a child. The link between a fetus and the child it can become when the fetus is previable can be established only by the pregnant woman's decision to confer the status of being a patient on her previable fetus. The previable fetus, therefore, has no claim to the status of being a patient independently of the pregnant woman's autonomy. The pregnant woman is free to withhold, confer, or, having once conferred, withdraw the status of being a patient on or from her previable fetus according to her own values and beliefs. The previable fetus is presented to the physician as a function of the pregnant woman's autonomy [10]. Some countries outlaw abortion of all previable fetuses, the result of which is ethically impermissible restriction of the pregnant woman's

autonomy by state power. Physicians in these countries should work for change in such public policies.

When the fetus is a patient, directive counseling for fetal benefit is ethically justified. "Directive counseling" means that the physician should make recommendations that would benefit the fetus. It is emphasized that directive counseling for fetal benefit must occur in the context of balancing beneficence- based obligations to the fetus against beneficence-based and autonomy-based obligations to the pregnant woman. Any such balancing must recognize that a pregnant woman is obligated only to take reasonable risks of medical interventions that are reliably expected to benefit the viable fetus or child later.

Obviously, any strategy for directive counseling for fetal benefit that takes account of obligations to the pregnant woman must be open to the possibility of conflict between the physician's recommendation and a pregnant woman's autonomous decision to the contrary. Such conflict is best managed preventively through the informed consent process as an ongoing dialogue throughout a woman's pregnancy, augmented as necessary by negotiation and respectful persuasion [5].

Critical care as a trial of management

Critical care should be understood not as an all-or-nothing intervention but as a trial of management that can justifiably be discontinued when its goals are unlikely to be met. This may seem a jarring concept when a younger, previously healthy population of patients, such as pregnant women, is concerned. However, conditions, diseases, or injuries that warrant admission of a pregnant woman to a critical care unit are by definition very serious, which means that the limits of medicine to alter the course of disease or injury may be reached in the course of a critical care admission. Losing sight of this clinical reality sets up ethical conflict for the physician, the critical care team, the patient, and her family. Critical care may reach such limits with respect to either its short-term or its long-term goals.

Critical care has a short-term goal, the prevention of imminent death. Critical care is usually very effective at achieving this goal. When it is no longer reasonable in evidence-based consideration to expect that imminent death can be prevented, there is no beneficence-based obligation to continue.

Critical care also has a long-term goal, survival with an acceptable outcome. "Acceptable outcome" should be understood from either a clinical or a patient's perspective. The clinical perspective is beneficence based. When critical care is no longer expected to achieve survival with at least some interactive capacity, there is no beneficence-based obligation to continue. The patient's perspective is autonomy based. When critical care is expected to achieve survival with at least some interactive capacity but with a quality of life not acceptable to the patient, there is no autonomy-based obligation to continue. "Quality of life" means engaging in life tasks such as family life and pursuing meaningful activities and deriving satisfaction from doing so. There is no philosophical theory to support any claim about what life tasks are worth pursuing and how much satisfaction from doing so is enough. These are matters for each patient to determine for herself.

The stopping rules for critical care as a trial of intervention should be based on whether the short- term goal can be achieved. When it is no longer reasonable to expect this goal to be achieved, the beneficence-based obligation to continue critical care as a trial of intervention no longer exists. The stopping rules should also be based on the whether the long- term goals can be achieved. When it is no longer reasonable to expect that the long-term goals, from either a clinical or patient's perspective, can be achieved, then, respectively, the beneficence-based obligation or the autonomy-based obligation to continue critical care as a trial of intervention no longer exists.

Maternal critical care is ethically more complex when the fetus is a patient. After viability, discontinuation of critical care management should include delivery of the fetal patient. This is because there is beneficence-based obligation to protect the fetal patient's life and health, and delivery, including immediate postmortem delivery, does not violate beneficence-based obligations to the pregnant woman. For the previable fetus, continuation of critical management for fetal benefit, including continuation after the pregnant woman is determined to be dead by accepted brain-function criteria, should be undertaken only when she has explicitly authorized this or when a valid surrogate authorizes it on the basis of the patient's wishes and there is a plan for the delivery of the viable fetal patient if continued critical care becomes ineffective in maintaining the pregnant woman in a stable condition.

A preventive ethics approach to decisions about maternal critical care

Preventive ethics uses the informed consent process to anticipate and prevent ethical conflict between patients and their physicians [5]. Preventive ethics should play a very prominent role in maternal critical care. There are distinctive, but complementary, roles for the physician and patient.

The physician's role is to explain to the pregnant patient before critical care is initiated its nature as a trial of management. The physician should explain both the short-term and the long-term goals and the possibility that they might not be achieved. The physician should explain that, if this becomes the case, discontinuing critical care management and discharging the patient to hospice care is the ethical standard of care. The patient's wishes should be elicited. The physician should make every effort to help patients who request that everything be done to understand that not every reduction in the risk of mortality is worth the disease-related and iatrogenic morbidity that result, because these can greatly reduce or even eliminate the ability of the patient to experience a quality of life that she would want for herself. Seriously ill patients who

"want everything done" often do not appreciate what this means in clinical reality, setting up preventable ethical conflict.

It is now possible for patients to formally express their wishes about maternal critical care in the form of what in the USA are called "advance directives", a concept and practice pioneered in the USA. The practice of medicine in the American federal system of self- government is regulated by the individual states. Spurred by the famous case of Karen Quinlan in New Jersey in 1976 [9], the first end-of-life case to be adjudicated, all states have enacted advance directive legislation [11]. Some states do not allow an advance directive to be applied to limit life-sustaining treatment of a terminally or irreversibly ill pregnant patient. This restriction has not been challenged in the courts.

The basic ethical idea of an advance directive is independent of how it is implemented in law and public policy in the USA. The ethical idea is that a patient, when autonomous, can make decisions regarding her medical management in advance of a time during which she becomes incapable of making her own healthcare decisions. The ethical dimensions of autonomy that are relevant here are the following. A patient may exercise her autonomy now in the form of a request for or refusal of life-prolonging interventions. Autonomy-based request or refusal, expressed in the past and left unchanged, remains in effect for any future time during which the patient becomes non-autonomous (i.e. in the clinical judgment of her attending physician, she no longer has decisionmaking capacity). That past autonomy-based request or refusal, therefore, creates the physician's obligations at the time the patient becomes unable to participate in the informed consent process. In particular, refusal of life-prolonging medical intervention should translate into the withholding or withdrawal of such interventions, including discontinuation of maternal critical care as a trial of intervention. This ethical reasoning can be applied clinically in countries without advance directive legislation, guided by competent legal advice.

The living will or directive to physicians is an instrument that permits the patient to make a direct decision, usually to refuse life-prolonging medical intervention in the future. The living will becomes effective when the patient is a "qualified patient", usually terminally or irreversibly ill, and is also not able to participate in the informed consent process as judged by her physician. Court review is not required. Obviously, terminally or irreversibly ill patients who are able to participate in the informed consent process retain their autonomy to make their own decisions. Some states prescribe the wording of the living will, and others do not. A living will, to be useful and effective, should be as explicit as possible. Readers in jurisdictions that sanction such advance directives should become familiar with them and with organizational policies for their preparation, documentation in the record, and implementation.

The concept of a durable power of attorney or medical power of attorney is that any autonomous adult, in the event that that person later becomes unable to participate in the informed consent process, can assign decision-making authority to another person. The advantage of the durable power of attorney for healthcare is that it applies only when the patient has lost decision-making capacity, as judged by his or her physician. Court review is not required. It does not, as does the living will, also require that the patient also be terminally or irreversibly ill. However, unlike the living will, the durable power of attorney does not necessarily provide explicit direction, only the explicit assignment of decision-making authority to an identified individual or "agent." Obviously, any patient who assigns durable power of attorney for healthcare to someone else has an interest in communicating his or her values, beliefs, and preferences to that person. The physician can play a facilitating role in this process. Indeed, in order to protect the patient's autonomy, the physician should play an active role in encouraging this communication process so that there will be minimal doubt about whether the person holding durable power of attorney is faithfully representing the wishes of the patient. The pregnant patient is free to name anyone of her choosing to act as her agent.

The main clinical advantages of these two forms of advance directives are that they encourage patients to think carefully in advance about their request for or refusal of medical intervention, and that these directives, therefore, help to prevent ethical conflicts and crises in the management, particularly, of terminally or irreversibly ill patients who no longer have decision-making capacity and for whom the stopping rules of critical care as a trial of intervention apply. The reader is encouraged to think of advance directives as powerful, practical strategies for preventive ethics for end-of-life care, and to encourage patients who are candidates for maternal critical care to consider them seriously. The use of advance directives prevents the experience of increased burden of decision making in the absence of reliable information about the patient's values and beliefs [2].

For patients without advance directives, medical ethics accepts surrogate decision making. Many legal jurisdictions do as well. Two standards, in priority, guide surrogate decision making. The first is the "substituted judgment" standard. This standard is autonomy based. This calls for the surrogate, as best as he or she can, to make decisions based on the values and beliefs of the patient. The physician can help surrogates to implement this standard by asking the surrogate to describe what was important to the patient, particularly life tasks that she valued. The physician can then provide his or her best judgment about the projected functional status of the patient and its implications for undertaking those life tasks. Doing so helps the surrogate to make a reliable decision about whether the long-term goal of critical care from the patient's perspective can be achieved. When a surrogate cannot meet the substituted judgment standard, which is

probably unlikely for a married pregnant patient, the best interests standard applies. This standard is beneficence based. The physician, therefore, plays a leading role in implementing this standard. When the short-term goal of critical care cannot be achieved, the physician should explain that this is the case and that it is consistent with good medical care to discontinue critical care and transfer the patient to a hospice program. The physician's role is the same when the long-term goal from a clinical perspective cannot be achieved.

Conclusions

Maternal critical care is an essential component of comprehensive obstetric care. Maternal critical care is ethically challenging because it involves recognizing the limits of medicine to alter the course of serious injury or disease in the context of pregnancy. Physicians should respond to these ethical challenges with a preventive ethics approach. Like all critical care, maternal critical care should be understood by physicians and presented to pregnant patients or their surrogates as a trial of management with both short-term and long-term goals. Beneficence-based and autonomy-based stopping rules for the trial of intervention should shape the physician's role in the informed consent process for continuation of maternal critical care. Patients in jurisdictions that provide for them should be encouraged to formalize their decisions with advance directives and to have open and honest discussions in advance with those who could become surrogate decision makers.

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